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First Nations Cancer Research and Surveillance Priorities for Canada

Workshop Report
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Executive Summary

The First Nations Cancer Research and Surveillance Workshop was designed to bring together a diverse group of cancer epidemiologists and researchers, First Nations leaders and health policy professionals, cancer agency representatives, and government officials to share information and perspectives about cancer research and surveillance as they relate to First Nations people. The main purposes were to identify cancer research and surveillance needs and priorities in Canadian First Nations populations and to create an action plan for moving forward in priority areas. Particular emphasis was given to discussion of the need for a national First Nations cancer surveillance system.

The imperative for action comes from knowledge that cancer incidence is increasing in First Nations populations, particularly incidence of preventable cancers such as lung cancer, and that survival following a cancer diagnosis is poorer than in the general population. A Needs Assessment conducted in Ontario First Nations communities further identified a lack of awareness of cancer and cancer prevention, lack of cancer research specific to Aboriginal populations in Canada, and a lack of appropriate cancer-related information for these communities.

The Workshop identified specific priority needs for research in the areas of cancer surveillance, risk determinants, outcomes, specific prevention and intervention. It also identified a number of general research-related needs including capacity-building, program evaluation, sustainable funding, longitudinal research, partnerships and communication. The findings of this Workshop have been presented to the major Canadian cancer research funding agencies (Canadian Institutes of Health Research Institutes of Cancer and Aboriginal Peoples' Health and the National Cancer Institute of Canada) to promote awareness of the need for cancer-related research in Canada's Aboriginal populations.

Workshop participants agreed that ongoing surveillance of cancer in Aboriginal populations is important and necessary. Significant barriers to implementation of a nationwide system were recognized. These include: the difficulty of accurately and completely identifying Aboriginal people in health data systems, particularly those who are not Status Indians; the need to develop methods and partnerships that respect the Aboriginal principles espoused in OCAP (ownership, control, access and possession); and the lack of capacity among Aboriginal people in the relevant technical and scientific disciplines.

The presence of several facilitating factors was also noted. First, databases recording all newly diagnosed cancers (cancer registries) are well established in all provinces, and are combined to form a Canadian Cancer Registry. Second, several provinces have demonstrated feasibility by periodically estimating the cancer burden in their First Nation populations; these efforts have used a variety of methodologies based on the provincial cancer registries, although not all methods are equally robust. Third, some provinces have infrastructure and collaborative arrangements in place to support further development of cancer surveillance systems.

Next steps towards building a nationwide First Nations Cancer Surveillance System include disseminating the workshop findings to stakeholders and encouraging them to begin planning for action; determining how cancer surveillance could be implemented consistent with OCAP; and developing provincial-level strategies for surveillance. In the province of Ontario, for example, Cancer Care Ontario is well positioned to take the lead. Cancer Care Ontario's Aboriginal Cancer Care Unit, supported by JOACC, and Surveillance Unit have produced cancer surveillance data for Ontario First Nations people and are working together to develop political-ethical and technical-scientific strategies for developing, maintaining and using an ongoing system.

Terminology

Terms relating to Aboriginal peoples have been used throughout this report in accordance with the definitions provided by the Communications Branch of Indian and Northern Affairs Canada[1]. These definitions, along with descriptions of technical terms used in the report, are provided below.

Aboriginal people(s)[1] - Collective name to describe the original peoples of North America and their descendants. The Canadian Constitution recognizes three groups of Aboriginal peoples - Indians, Métis and Inuit. These are three separate peoples with unique heritages, languages, cultural practices and spiritual beliefs.

Canada Health Infoway - Independent, not-for-profit corporation with a mandate to facilitate and accelerate the development and adoption of electronic health information systems in Canada. Its priority is electronic health record solutions and related telehealth development.

Cancer - A group of related diseases in which abnormal cells divide without control. Cancer can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

Cancer Precursor - A medical condition that can sometimes progress to cancer.

Cancer Registry - A database that contains information on patients newly diagnosed with cancer. In Canada, every province/territory has a cancer registry and all provide a copy of the data pertaining to its residents to Statistics Canada to create the Canadian Cancer Registry.

Carcinogen - A substance that causes cancer.

Diabetes mellitus - a condition characterized by hyperglycemia (excessive blood glucose) resulting from the body's inability to use blood glucose for energy. In type 1 diabetes, the pancreas no longer makes insulin and therefore blood glucose cannot enter the cells to be used for energy. In type 2 diabetes, either the pancreas does not make enough insulin or the body is unable to use insulin correctly.

Early Detection - A process or test that allows a cancer to be diagnosed before reaching the stage where there are symptoms. Generally, cancers diagnosed earlier can be more successfully treated.

Epidemiology - The study of the patterns of diseases in human populations, and the factors that influence the patterns.

Etiology - The postulated causes of a disease or disability that initiate the pathogenic mechanisms; control of these causes might lead to prevention of the disease.

First Nation(s)[1] - A term that came into common usage in the 1970s to replace the word "Indian". Although the term First Nations is widely used, no legal definition of it exists. Among its uses, the term "First Nations peoples" refers to the Indian peoples in Canada, both Status and Non-Status. Some Indian peoples have also adopted the term "First Nation" to replace the word "band" in the name of their community.

First Nations and Inuit Health Branch (FNIHB) - A Branch of Health Canada that supports the delivery of public health and health promotion services on-reserve and in Inuit communities. It also provides drug, dental and ancillary health services to First Nations and Inuit people regardless of residence. The Branch also provides primary care services on reserve in remote and isolated areas, where there are no provincial services readily available.

Genetic - Inherited; having to do with information that is passed from parents to offspring.

Geographical Information Systems (GIS) - A computer system capable of capturing, storing, analyzing, and displaying geographically referenced information; that is, data identified according to location. Can also include the procedures, operating personnel, and spatial data that go into the system.

Glucose - A simple form of sugar that is the chief source of energy for living organisms.

Health Promotion - The process of enabling individuals to increase control over and improve their health. It involves the population as a whole in the context of their everyday lives, rather than focusing on people at risk for specific diseases, and is directed toward action on the determinants or causes of health.

Health Status - A general term for the state of health of an individual, group or population that reflects the degree to which a person is able to function physically, emotionally, and socially, with or without aid from the health care system.

Helicobacter pylori - Bacteria found in the stomach that can damage the lining of the stomach and upper small intestine, leading to ulcer formation. Recently recognized as a cause of stomach cancer.

Hormones - Chemicals produced by glands in the body that circulate in the bloodstream and control the actions of certain cells or organs.

Identifier - A piece of information, such as name, health insurance number, date of birth, etc., that distinguishes one individual or family from another. Often more than one such piece of information is required to uniquely identify an individual. Identifiers are required to conduct record linkage.

Incidence Rate - The number of people who develop a disease divided by the number of people at risk of developing the disease in a specific time period. For cancer, it is generally expressed per 100,000 persons per year.

Indian and Northern Affairs Canada (INAC) - The federal government department that is responsible for two separate yet equally important mandates: Indian and Inuit Affairs and Northern Affairs. In general, INAC has primary, but not exclusive, responsibility for meeting the federal government's constitutional, treaty, political and legal responsibilities to First Nations, Inuit and Northerners. In Indian and Inuit Affairs, the department's role is to support First Nations and Inuit in developing healthy sustainable communities and in achieving their economic and social aspirations. In Northern Affairs, INAC is the principal federal department responsible for meeting the federal government's constitutional, political and legal obligations in the North.

Indian Health Service - The U.S. governmental body responsible for some health services in Native Americans.

Infant Mortality Rate - The number of deaths in children less than one year old divided by the number of live births in the same year.

Insulin - A hormone made in the pancreas that helps the body use glucose for energy.

Insulin Resistance - The body's inability to respond to and use the insulin it produces.

Inuit[1] - The Aboriginal people of Arctic Canada. Inuit live primarily in Nunavut, the Northwest Territories and northern parts of Labrador and Quebec. They have traditionally lived above the treeline in the area bordered by the Mackenzie Delta in the west, the Labrador coast in the east, the southern point of Hudson Bay in the south, and the High Arctic islands in the north.

Leukemia - A type of cancer that forms from cells in the blood and bone marrow, including leukocytes or white blood cells that help the body fight infections and other diseases.

Life Expectancy - The age to which an individual would be expected to live if current mortality rates continued to apply.

Lipids - Fatty substances in blood and body tissues, including cholesterol and triglycerides.

Longitudinal research - Studies where individuals are followed over time. Data may be collected periodically or just at the beginning and end of the time period.

Mammography - A technique that uses low-dose x-rays to find tumors in the breast. Most commonly used for early detection.

Métis[1] - The French word for "mixed blood." The Canadian Constitution recognizes Métis people as one of the three Aboriginal peoples. Historically, the term "Métis" applied to the children of French fur traders and Cree women in the Prairies, and of English and Scottish traders and Dene women in the North. Today, the term is used broadly to describe people with mixed First Nations and European ancestry who identify themselves as Métis, distinct from Indian people, Inuit, or non-Aboriginal people. (Many Canadians have mixed Aboriginal and non-Aboriginal ancestry, but not all identify themselves as Métis.) Métis organizations in Canada have differing criteria about who qualifies as a Métis person.

Mortality Rate - A measure of the rate at which deaths occur in a population. The number of persons dying of either any cause or one specific cause divided by the number of people at risk of dying in a specific time period. For cancer, it is generally expressed per 100,000 persons per year.

National Aboriginal Health Organization (NAHO) - An Aboriginal-designed and controlled body established to influence and advance the health and well-being of Aboriginal peoples through carrying out knowledge-based strategies.

Native American[1] - Commonly used term in the United States to describe the descendants of the original peoples of North America. The term has not caught on in Canada because of the apparent reference to U.S. citizenship. However, some Aboriginal peoples in Canada have argued that because they are descendants of the original peoples of the *Americas*, the term Native American should apply to them regardless of their citizenship.

Obesity - An excessive amount of body fat. Obesity is considered to be present when one's body mass index (BMI) is 30 or more. BMI is a weight to height ratio, calculated as [weight (in kilograms)] divided by [height (in metres) squared].

Ownership, Control, Access and Possession (OCAP) - Principles under which First Nations control data collection processes in their communities. First Nations own, protect and control how information about themselves and their communities is used. Access to First Nations data is important and First Nations determine, under appropriate mandates and protocols, how access can be facilitated and respected.

Pap (Papanicolau) Test - A simple test that can detect precursors of cancer of the cervix. These precursors can be treated so cancer does not develop. A few cells are gently scraped off the surface of the cervix, spread onto a glass slide and sent to a laboratory for examination under the microscope.

Polyp (colonic) - A benign growth protruding from a mucous membrane in the colon or rectum. Some polyps are cancer precursors. Their removal during procedures such as colonoscopy may prevent development into cancer.

Prevalence - The number of people who have a characteristic or disease at a particular time (or during a particular period) divided by the population at risk of having the characteristic or disease at this point in time.

Prognosis - The expected outcome of a disease and its treatment. In the case of cancer, this may be influenced by a variety of factors such as stage and age, and the particular type of cancer. For example, in general a patient with localised disease may have a more favourable prognosis compared to a patient with widespread disease.

Record Linkage - A method for bringing together two or more records with some attribute in common – usually that they pertain to the same individual.

Risk (Protective) Factor - Anything that has been identified as increasing (decreasing) an individual's chance of getting a disease.

Screening - The presumptive identification of clinically unrecognized disease by the application of tests, examinations or other procedures that can be applied rapidly and readily. Screening is an initial examination only, and those with a positive outcome require a second, diagnostic examination to ensure a correct diagnosis.

Socio-Economic Status (SES) - An indicator based on income, education and occupational prestige.

Stage at diagnosis - An indicator of how far a cancer has spread when diagnosed. The precise staging system used depends on the type of cancer. Low stage tumours are confined to the organ of origin, whilst high stage have metastases (spread to parts of the body far from the organ of origin). The treatment given will depend upon the stage of which a tumour is diagnosed. In general, those with low stage have a better prognosis.

Surveillance, Epidemiology, and End Results (SEER) - A program of the U.S. National Cancer Institute. SEER is a system of cancer registries with standardized inclusion criteria and quality control covering 10-15% of the U.S. population. It is recognized as an important source of information on cancer incidence and survival in the United States.

Survival Rate - The proportion of those with a given disease who survive for some defined length of time after diagnosis.

Status Indians (SI)[1] - People who are entitled to have their names included on the Indian Register, an official list maintained by the federal government. Certain criteria determine who can be registered as a Status Indian. Only Status Indians are recognized as Indians under the *Indian Act*, which defines an Indian as "a person who, pursuant to this Act, is registered as an Indian or is entitled to be registered as an Indian." Status Indians are entitled to certain rights and benefits under the law.

Surveillance - The ongoing systematic collection, analysis and interpretation of outcome-specific data for use in the planning, implementation and evaluation of public health practice.

Status Verification System (SVS) - Database maintained by Indian and Northern Affairs Canada (INAC) to identify First Nations people who are entitled for federal benefits (i.e., Status Indians).

[1] Words First – An Evolving Terminology Relating to Aboriginal Peoples in Canada. Communications Branch: Indian and Northern Affairs Canada, October 2002.

First Nations Cancer Research and Surveillance Workshop

A Overview

> "There is no word for cancer in my language. In Ojicree we call it Kitchi-Akoosowin, the Great Sickness."
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The First Nations Cancer Research and Surveillance Workshop was designed to bring together a diverse group of cancer epidemiologists and researchers, First Nations leaders and health policy professionals, cancer agency representatives and government officials to share information and perspectives about cancer research and surveillance as they relate to First Nations people. (See Agenda, Appendix A.) Although it is understood that Canada's Indigenous population encompasses First Nations, Aboriginal, Métis, and Inuit peoples, the workshop focused on First Nations people in Canada, as a first step. Most participants worked in Canada, although a few researchers from the U.S. and Australia were also invited to provide external perspective. (See Participant List, Appendix B)

The main goals of the workshop were to:

1. Identify cancer research and surveillance needs and priorities in Canadian First Nations populations and create an action plan for moving forward with research in priority areas.
2. Identify those working in First Nations cancer research and surveillance in Canada and establish networks among these individuals.
3. Identify the political, ethical, technical and scientific issues in relation to the conduct of First Nations cancer research and surveillance.
4. Discuss the need for a national First Nations cancer surveillance system as a tool for developing, implementing and evaluating cancer control in the First Nations population.

As background material, participants were provided with a bibliography of cancer-related publications in North American Aboriginal Populations for the period 1993-2004 (Appendix C) and a background issues paper on the "Benefits of a Cancer Surveillance System for Canada's First Nations People" (prepared by staff of Cancer Care Ontario; see Appendix D).

Each day of the two-day workshop had a distinct focus. Day one focused on research findings, gaps, challenges and priorities (reported in Section B.). Day two focused on the benefits and challenges to conducting cancer surveillance in First Nations populations (reported in Section C.).

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B Cancer Research in Canadian First Nations Populations

B.1 Knowledge and Gaps

Presentations on the first day of the workshop focused on cancer research that has been done in Ontario, Manitoba, British Columbia, Alaska, and Australia, including:

1) Current knowledge about the burden of cancer in Aboriginal populations: incidence patterns and trends; mortality and survival (see Tables 1 and 2).
2) Knowledge of cancer risk factors and early detection behaviours in First Nations people in Canada.
3) Cancer-related needs and issues from the perspective of Ontario First Nations.

B.1.1 Summary of Research Findings

- Cancer has historically occurred at a lower rate in Aboriginal populations; however rates are increasing – dramatically in some regions and for some cancers.
- Survival is poorer in First Nations populations than in the general population; later stage at diagnosis appears to be only part of the explanation.
- There is considerable regional variation in incidence and/or mortality within North America and between North American and Australian Indigenous peoples.
- With respect to cancer risk determinants and early detection behaviors:
    - The prevalence of cigarette smoking is high in Aboriginal populations so lung cancer incidence is expected to continue to increase.
    - Historically, uptake of Pap test screening by Aboriginal women has been lower than that in the general population, although special efforts to increase it may have produced recent reductions in the incidence of cancer of the cervix.
    - The high prevalence of Type II diabetes in First Nations populations may result in future increases in the incidence of so-called 'western cancers' (cancers of the breast, prostate and colorectum).
- The Aboriginal Cancer Needs Assessment conducted in Ontario identified the need for prevention and education programs, and for more data about the burden of cancer in Ontario First Nations populations.

B.1.2 The Burden of Cancer

Table 1: Cancer Incidence

Region	*Findings*
Canada	
Ontario	▪ Incidence for all cancers combined is lower in the First Nations population than the Ontario population. ▪ Incidence is similar in the two populations for kidney, mouth, throat and stomach cancers in both sexes, and colorectal cancer in men. ▪ In the First Nations population, incidence is increasing for all cancers combined and for the four most common cancers: breast, prostate, lung and colorectal. Rates are approaching the Ontario rates for colorectal and lung cancers. ▪ Cervical cancer, which has historically had a higher incidence in the First Nations population, has been declining and is approaching the Ontario rate.
Manitoba	▪ Cervical cancer in women and kidney cancer in both men and women are higher in the First Nations population than in the Manitoba population.
British Columbia	▪ Cervical cancer is higher in the First Nations population than the British Columbia (B.C.) population. ▪ Pancreas and stomach cancers and leukemia have about the same incidence in the First Nations community and the B.C. population.
United States	
Native Americans	▪ The most common cancers in the Native American population, in order, are: lung, prostate, colorectal, breast, stomach, liver, and cervix.
Alaska	▪ Cancer incidence in the Alaskan Native population is now equal to or higher than that in the U.S. white population. Alaskan Native women have the highest cancer rates of all racial/ethnic groups in the U.S. ▪ The most common cancers in the Alaskan Native population are breast and lung cancers in women and lung and prostate cancers in men. ▪ Cervical cancer, which was previously higher in Alaskan Native women, is now less common than in the U.S white population.
Australia	
Northern Territories	Incidence rates are higher among Indigenous people for lung, liver, and cervix cancers. Rates of smoking-related cancers have almost doubled in the last 40 years.

Table 2: Cancer Mortality and Survival

Region	*Findings*
Canada	
Ontario	Survival is significantly worse for all cancers combined for the First Nations population, compared to the Ontario population. The survival rate for prostate cancer is significantly worse in First Nations men than in the general population. The survival rate for breast cancer is significantly worse in First Nations women. Survival is similar for other major cancers (lung, colorectal and cervix cancers).
British Columbia	Survival for all cancers combined appears similar for First Nations and non-First Nations people. Stage distribution at presentation appears similar for all cancers except for breast cancer, which is diagnosed at a later stage in First Nations women.
Saskatchewan	Breast cancer survival is poorer in northern First Nations than southern non-First Nations populations, even after adjustment for stage. Cervical and colorectal cancer survival is similar in the two populations.
United States	
Regional variations are marked:	Mortality rates for all cancers combined are lower for all Native Americans than for the all US population. However, stomach, liver, kidney, cervix and gallbladder cancers have higher mortality rates in Native Americans. In comparison to the all Native American and all U.S. populations, mortality is higher: • for all cancers combined and for lung cancer in the Northern Plains and Alaskan Native American populations. • for colorectal cancers in the Alaskan and Northern Plains populations. • for stomach cancer in the Alaskan, Southwest, and Northern Plains populations. • for cervical cancer in the Northern Plains, East and Southwest populations • for prostate cancer in the Northern Plains
Australia	
Northern Territories	• Indigenous Australians have higher mortality and lower survival for all cancers than the Australian population. • Mortality rates are higher among Indigenous people for lung, liver, and cervix cancers. • Survival is poorer for the Indigenous population than the total Australian population for cancers of the colon and rectum, cervix, breast and prostate, and for melanoma and lymphoma.

B.1.3 Risk Determinants and Early Detection Behaviors

Cigarette smoking

Lung cancer is one of the most common cancers in both Indigenous and non-Indigenous populations, and its incidence is increasing in a number of the regions, as shown in Table 1. The relationship between lung cancer and smoking is evident in U.S. Native American data, where the regions in which smoking by Native Americans is most prevalent have the highest incidence of lung cancer. In Australia, Indigenous people smoke at a rate that is approximately twice that of all Australians, and the incidence of lung cancer is higher in the Indigenous population than in the Australian population.

Pap test screening

Cervical cancer has historically been more common among Indigenous women than women in the general population, and the rates of participation in Pap screening have also been lower among Indigenous women.

A number of jurisdictions have taken steps to increase Pap screening for this population. In Alaska, where cervical cancer is now less common among Alaska Natives than among U.S. whites, community screening programs are thought to have assisted in reducing the incidence of cervical cancer.

In British Columbia, where mortality from cervical cancer was much higher amongst First Nations women and Pap testing was much lower, a study was undertaken about how best to implement a screening program among First Nations women in Vancouver. Challenges included identifying and locating First Nations women and engaging the women in First Nations screening clinics in a way that would increase their participation in screening. It was found that having a trusting relationship with their caregiver was critical for them to make use of the screening services available.

In Nova Scotia, letters to women reminding them about the importance of Pap screening were tested for their effectiveness in increasing screening participation. Research found that receiving a letter improves somewhat the likelihood that a woman will participate in Pap screening. This was also true for areas of the province with high proportions of Aboriginal women or of black women.

Diabetes

There may be epidemiologic and biologic links between diabetes and some common types of cancer such as colorectal cancer. To the extent that this is true, there is reason for concern, given the high prevalence of diabetes in First Nations populations.

Epidemiologically, there are a number of factors that increase the risk of both diabetes and colorectal cancer, in particular physical inactivity, obesity and some aspects of what we eat. Furthermore, it is biologically plausible that the changes associated with diabetes (and the state of insulin resistance that often precedes it) may facilitate the growth of cancer cells. Disrupted physiology in Type II diabetes results in increased levels of glucose, lipids, insulin and other hormones. Cancer cell growth is dependent on energy (such as that provided by glucose), and stimulating hormones such as insulin.

There is accumulating epidemiologic evidence that the changes that occur with diabetes/insulin resistance are associated with increased risk of colon cancer; one might expect similar associations with breast and other cancers that are related to obesity. The precise nature of these associations is uncertain, because study of these associations has occurred only over the past few years.

B.1.4 Aboriginal Cancer Needs Assessment

Cancer Care Ontario recently conducted a Cancer Needs Assessment. It found that First Nations communities face a number of issues that have a significant impact on health, including risk of cancer. Some highlights include:

- There is a lack of culturally appropriate cancer-related information available to Aboriginal communities.
- There is a myth in Aboriginal communities that cancer is not treatable, and a widespread belief held by health professionals that cancer is not a problem for First Nations people.
- Aboriginal communities have to cope with complex and fragmented health care systems.
- Although the First Nations population is young, cancer will become an increasingly important problem as the population ages.
- There is a lack of research data specific to Aboriginal populations, and much of what does exist is focused on Native American populations.
- Challenging life circumstances – poverty, social conditions, etc. – experienced by many Aboriginal people negatively impact cancer incidence, survival and prevention.

The key findings of this study include the need for improved prevention and education programs, as well as for more data about the burden of cancer in Ontario First Nations. The latter is important for identifying priorities, planning programs and conducting evaluation.

B.2 Research Priorities

The framework in Figure 1 will be used to categorize research issues and priorities that were identified by workshop participants.

Figure 1.
Framework for cancer research priorities in First Nations populations

Table 3: Research Priorities

Surveillance	
Cancer surveillance research was generally identified as a priority area for further development. Surveillance data can provide clues to etiology (e.g., via regional comparisons), assist in development of cancer control priorities and be used to evaluate outcomes and the effectiveness of prevention and screening programs and other interventions.	
Data	• Compare cancer rates for First Nations populations in Canada and the U.S., nationally and by region. • Determine how surveillance data can be produced for Aboriginal populations other than First Nations. • Explore strategies to streamline surveillance across chronic diseases.

Methodology	• Systematically investigate the quality of data in the Status Verification System for use in cancer surveillance.
	• Develop better surveillance tools for study of small populations such as First Nations. Issues requiring attention include:
	  ○ Data collection
	  ○ Contrasts and interpretation
	  ○ Reporting to communities

Precursors	• Conduct surveillance research to identify, monitor and study causes of cancer precursors related to possibly increased risk, e.g., screening for colonic polyps. (See earlier section on potential links between colorectal cancer and Type II diabetes.)

Risk Determinants	
There have been few studies of determinants of cancer risk in First Nations populations. Research should capitalize on the known differences in risk profile between First Nations and general populations vis à vis cancer patterns, smoking rates, diabetes, uptake of screening, environmental settings and general socio-economic status.	
Genetic factors	• Are there true genetic differences that underlie differences in cancer incidence. If so, can this information help to tailor preventive efforts? • Is there a genetic explanation for their low rates of bladder cancer, given high smoking rates in First Nations people and the strong association between bladder cancer and smoking in the general population?
Environmental factors	• Is cancer incidence increasing in relation to changes to the natural environment? e.g., building of the Yukon highway • What are the links between cancer and environmental contaminants? • Can mapping (e.g., through use of geographic information systems or GIS) be a tool to study links between environmental contamination and cancer burden? • Do airborne carcinogenic contaminants affect cancer rates in First Nations communities due, for example, to a different distribution of climatic patterns?
Other risk determinants	• What is the role of obesity and inactivity in increasing cancer rates in First Nations people? • What are the underlying psychosocial causes of cancer-related risk behaviors? • What are the impacts on cancer incidence of health determinants such as poverty, poor water quality, poor housing, geographic isolation? • Are there links between stress and cancer? • Are First Nations people with diabetes at increased risk of cancer? • How important are infectious agents such as *Helicobacter pylori*?

Table 3: Research Priorities

Surveillance	
Cancer surveillance research was generally identified as a priority area for further development. Surveillance data can provide clues to etiology (e.g., via regional comparisons), assist in development of cancer control priorities and be used to evaluate outcomes and the effectiveness of prevention and screening programs and other interventions.	
Data	• Compare cancer rates for First Nations populations in Canada and the U.S., nationally and by region. • Determine how surveillance data can be produced for Aboriginal populations other than First Nations. • Explore strategies to streamline surveillance across chronic diseases.
Methodology	• Systematically investigate the quality of data in the Status Verification System for use in cancer surveillance. • Develop better surveillance tools for study of small populations such as First Nations. Issues requiring attention include: – Data collection – Contrasts and interpretation – Reporting to communities
Precursors	• Conduct surveillance research to identify, monitor and study causes of cancer precursors related to possibly increased risk, e.g., screening for colonic polyps. (See earlier section on potential links between colorectal cancer and Type II diabetes.)

Risk Determinants	
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Outcomes

The limited available data suggest that Aboriginal people have poorer survival for at least some cancers, and that this is not entirely attributable to a less favourable distribution of cancer stage at diagnosis. Research into reasons for the survival disadvantage is required so that inequities can be addressed.

- What factors, in addition to stage, are important determinants of survival differences?
- What are the roles of socio-economic status, treatment, co-morbidity?
- How comparable is cancer stage information across populations and jurisdictions; how can it be improved?
- What is the impact of traditional Indigenous medicine (treatment, ceremonies, and medicines) on cancer outcomes?
- What are the patterns of access to diagnosis and treatment and what is their effect on outcome?
- What is the impact of a fragmented health care system on outcomes?

Prevention and Intervention

General issues in prevention and intervention research relate to cultural appropriateness and sensitivity, access and barriers.

Prevention	• What are the patterns of use of clinical preventive services such as Pap tests and mammograms? What are the barriers to uptake of these? How can delivery/uptake be improved? • Are there lessons from mainstream tobacco reduction strategies that could be applied to tobacco reduction initiatives for First Nations? • How can positive lifestyle changes be impacted? • Are there benefits to focusing prevention efforts on children? • Conduct formal evaluations of Aboriginal smoking reduction and cessation programs to find what works. • Conduct evaluations of other prevention initiatives to determine what has worked in First Nations populations. • Develop and evaluate comprehensive prevention/health promotion strategies based on best practices. • Evaluate effectiveness of educational strategies.
Culture	• What is the role of self-perceived health in health care seeking behaviour in First Nations populations? • What are the best practices in transcultural training? • What is the role and impact of traditional healers? • What is the impact of collaboration between traditional healing models and western medicine on effectiveness of cancer risk reduction strategies? • What are the best practices with respect to culturally sensitive communication and messaging?
Access	• What are the patterns of use of prevention and screening services? How can knowledge of these be used to improve services? • What is the impact of a fragmented health care system on access to diagnosis and treatment?

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Access	▪ What are the patterns of use of prevention and screening services? How can knowledge of these be used to improve services? ▪ What is the impact of a fragmented health care system on access to diagnosis and treatment?

B.3 General Research Needs and Challenges

There are a number of general research-related needs that were identified during the course of the discussion, including:

- More long-term, longitudinal research (including surveillance), although this is difficult in a small population;
- More and better evaluation of programs;
- Sustainable funding for research and prevention programs;
- More trained Aboriginal epidemiologists and other scientists;
- Partnerships across regions, organizations (including Aboriginal and governments) and between countries;
- Protocols and agreements for data-sharing that satisfy ethical and moral considerations;
- More and better prevention-focussed communication;
- Consistent definitions and clearer language;
- Greater awareness of cancer as a priority area of research in First Nations people;
- Translation of what has already been researched into action that can benefit individuals;
- More strategic use of research findings;
- Communication of research findings to Aboriginal communities.

Some challenges specific to research in First Nations populations were also identified:

- Multi-jurisdictional responsibility for health care;
- Privacy issues;
- Cultural appropriateness;
- Language barriers and geographic isolation of some communities;
- Establishment of trust;
- Ownership, Control, Access and Possession (OCAP) of data.

B.4 Keynote Address

> **"We must work together to solve the difficulties of data collection. We need answers. We need awareness"**
>
> ***Ontario Regional Chief Charles Fox***

Day 1 of the workshop concluded with a keynote dinner address by Ontario Regional Chief Charles Fox, Vice-Chief and Chair of the Health Committee, Assembly of First Nations.

Chief Fox spoke passionately about the critical importance of research on the determinants of cancer and surveillance of the cancer burden in First Nations people. He mentioned the need to address the myth that cancer is rare amongst First Nations peoples, noting that this may contribute to mis- or late diagnosis.

Chief Fox called for advocacy, compassion and sensitivity, touching on many of the issues that had been identified during the first day of the workshop. As well, he set the stage for the deliberations of Day 2 when he spoke of the need to work together to solve the difficulties of data collection. In concluding his address, he reminded the audience to respect the principles of OCAP and pledged support for development of a cancer research agenda for First Nations people.

C Cancer Surveillance in Canadian First Nations Populations

The second day of the workshop focused on political, ethical, technical, cultural and scientific issues in relation to the conduct of First Nations cancer surveillance, and on developing options and specific "next steps" for improving and expanding cancer surveillance.

C.1 Surveillance

Surveillance, as noted in the definition below, involves both collection of information and its use for health planning.

> **surveillance**: "the ongoing systematic collection, analysis and interpretation of outcome-specific data for use in the planning, implementation and evaluation of public health practice" (Thacker SB, Berkelman RL. Public Health Surveillance in the United States. Epidemiologic Reviews.1988;10:164-90).

Ideally, the data collection for surveillance is ongoing and routine rather than periodic. Surveillance systems such as the Ontario Cancer Registry, the Ontario mortality database and the Canadian Injury Surveillance Program represent the former situation while risk factor surveys are an example of the latter. An ongoing surveillance system is better than ad hoc surveys for a comprehensive picture of population health needs. Although death data are available in the form of a surveillance system, the data are collected for the purpose of registering the fact of death as required by government. Nevertheless, they are useful for monitoring rates of mortality. This illustrates that in some situations data that were not collected for surveillance can be used for surveillance purposes.

Surveillance data can be used to address several types of public health issues, including quantification of the magnitude of a health problem; assessment of prognosis; detection of areas of priority need; evaluation of prevention or control measures; and monitoring of changes in the frequency and distribution of a health event over time.

C.1.1 Cancer Surveillance Systems

Within the population as a whole, systems for cancer surveillance are well developed in Canada. Each province maintains a cancer registry – essentially a cancer surveillance system with data on all newly diagnosed cancers - for its residents. They are generally operated by agencies that are at arms' length from the provincial governments. These registries can routinely produce cancer incidence, mortality and survival statistics for their respective populations. While registries differ in their registration procedures, contents and duration, they all cover their entire provincial populations, are of acceptable-good quality and contain at least 20 years of cancer diagnoses. Since 1992, they have been combined at the national level into the Canadian Cancer Registry. Population-wide cancer information is also collected for populations of the territories and these

are also included in the Canadian Cancer Registry. None of the provincial registries includes information on race or ethnicity.

C.2 First Nations Peoples' Health Status

The health status of First Nations peoples is generally poorer than that of the Canadian population. For example, Health Canada's 2003 profile of 437,035 First Nations people living on reserve in 1999 found that:

- Life expectancy is low: First Nations males live 68.9 years and females, 76.6 years, compared to Canadians, who can expect to live 76.3 years (males) or 81.8 years (females);
- The infant mortality rate is 1.5 times the Canadian rate;
- First Nations people die younger, and at a higher rate than Canadians;
- 20-24 year olds are dying at 4 times the Canadian rate;
- Leading causes of death are injury and poisoning (most common cause in 1-44 year olds); circulatory disease; cancer; respiratory disease
- The suicide rate is twice as high as that for Canadians, except in those over 65 years;
- There is a disproportionate burden of infectious and sexually transmitted disease compared with all Canadians;
- Smoking rates are double the Canadian average;
- Fewer complete high school than Canadians, although there has been a dramatic improvement from 37% in 1988 to 74% 1998;
- The unemployment rate on-reserve in 1997-98 was 36% vs.10% for Canadians;
- Shelter and adequate housing remain problems, with overcrowding increasing the risk of infectious disease transmission.

C.3 First Nations Health Surveillance

C.3.1 Overview

Surveillance of the health of First Nations populations is less developed than that of the Canadian population generally. For example, the statistics noted above are restricted to those living on reserve because identification of First Nations people not on reserve is generally not possible within Canada's national statistics systems.

Yet the need for improved health surveillance in First Nations has been identified and is supported by First Nations leaders and health professionals. It has been so identified in numerous reports by a variety of bodies, including the Federal/Provincial/Territorial Advisory Committee on Population Health, the Health Transition Fund, the Ministerial Advisory Council on Health Infostructure and the Romanow Commission.

Ontario Grand Chief Charles Fox, in his keynote address, made clear the interdependent impacts of inadequate prevention, diagnosis and treatment on the health of First Nations populations. He spoke passionately about how an adequate cancer surveillance system could support the development of initiatives and strategies to reduce the burden of cancer in First Nations

populations, from prevention and early detection through treatment and supportive care. Without data, communities can do little about controlling cancer burden.

C.3.2 Feasibility of First Nations Cancer Surveillance

Despite the lack of ethnicity/race information in Canadian cancer registries and mortality databases, the technical feasibility of producing cancer surveillance data for First Nations populations has been demonstrated by special studies in several provinces (see examples in Table 1). Different methods of identifying First Nations people can be used, including residence codes for reserves; a First Nations indicator in health insurance numbers; record of Native Indian ethnicity on death certificate; and linkage with the Status Verification System (SVS).

Table 4. Methods used to Identify First Nations People within Health-related Surveillance Systems in Canada

Method	*Description*	*Limitations*
Residence on a reserve	▪ There are specific postal (or other area) codes for reserves which are included on some files	▪ Includes non-FN living on reserve ▪ Excludes First Nations living off reserve
Identification of health card numbers that belong to First Nations individuals	▪ In some provinces, First Nations individuals can be identified through their health card numbers	
Aboriginal ethnicity on death certificate	▪ Some provinces collect this information at time of death	▪ Accuracy unknown, based on next of kin report
Linkage with the Status Verification System maintained by Indian and Northern Affairs Canada	▪ The SVS includes all registered First Nations individuals living on or off reserve who are eligible for federal benefits through Indian and Northern Affairs Canada or the First Nations and Inuit Health Branch of Health Canada	▪ Personal identifying data on the SVS may not be of high enough quality for accurate data linkage ▪ SVS may be out of date and include people no longer resident in the jurisdiction

A methodological issue of importance when *rates* of cancer in First Nations populations are required is the difficulty of assembling estimates of the population at risk (i.e., numbers of First Nations people at risk of being diagnosed with cancer within the jurisdiction of the surveillance system according to age, sex, geography, etc.). When accurate population estimates are not available, the validity of surveillance results is compromised. The most important characteristic of population estimates is that they include all those who would be identified with cancer should they be diagnosed. Thus, census data may not provide valid estimates for those identified as First Nations according to the SVS.

Early cancer surveillance work often had small samples or other limitations that restricted generalizability, but more recent studies using Status Indian indicators or files in Saskatchewan, British Columbia and Ontario have overcome many of these limitations and produced reliable statistics which can be used for monitoring and planning.

C.4 Key Issues for Surveillance in First Nations Populations

The gathering of health information about First Nations people takes place against the backdrop of the history between Indigenous people and the colonizing government. This legacy has led First Nations to be deeply suspicious of the uses to which data about their health might be put.

The design, implementation and management of a First Nations health surveillance system requires resolution of issues such as those noted in Table 5.

Table 5: First Nations Cancer Surveillance - Key Issues

Political and Ethical Issues
▪ Governance ▪ Value judgments re selection of health indicators ▪ Privacy and data security ▪ Individual vs. collective rights ▪ Dimensions of consent
Areas of Human Resources and Capacity Development
▪ Health surveillance requirements ▪ Data collection/integration/analysis/interpretation ▪ Surveillance products/dissemination ▪ Management/coordination/legislation/regulation ▪ Basic research/applied research/knowledge synthesis ▪ Community and regional level capacity ▪ Data input ▪ Utilization ▪ Coordination and integration ▪ Sustainable long-term funding

C.4.1 Political and Ethical Issues

First Nations control and management of health data are seen as important components of self-government. However, provincial/territorial and federal governments and health agencies generally control and manage the collection and analysis of health information for the entire population, including First Nations.

First Nations peoples have agreed on a set of principles related to research that makes a natural link between self-determination and control over information about them. The principles are ownership, control, access and possession, referred to collectively as ***OCAP***. The widespread adoption of OCAP would do much to ensure principled arrangements between government, health agencies and First Nations. To date, there is little experience in implementing arrangements based on this code, although Indian and Northern Affairs Canada has recently established a policy requiring First Nations approval and participation for the sharing of its data with a provincial agency.

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The National Aboriginal Health Organization has proposed a number of steps to begin using OCAP:

- Active engagement of and direction by First Nations people in Health Canada's public health surveillance strategy;
- Support for an integrated, comprehensive First Nations surveillance strategy to identify priorities; and
- An implementation plan, with OCAP provisions at its core.

The National Aboriginal Health Organization has also identified the need for clear community benefits arising from health surveillance. First Nations priorities must drive investments, initiatives and systems development, and flexible design should reflect diversity across First Nations communities and regions

C.4.2 Human Resources and Capacity Issues

In order for First Nations to take leadership on health surveillance in their people, they must have the capacity to participate knowledgeably in the development, implementation and use of surveillance systems, in partnership with key players in the broader health information sector. Some of the required areas of development are listed in Table 4.

C.5 Technical and Data Issues

Conducting cancer surveillance in First Nations populations presents some technical challenges. These include availability and quality of data identifying people as members of First Nations; complexity of computerized record linkage techniques and software; lack of optimal concordance of identifying variables available on health and administrative data files; small numbers of First Nations people in many provinces/territories (i.e., at the jurisdictional level at which health information is managed); comparability of population and health system data. There are provincial variations in public health capacity, so that cancer surveillance is more feasible in some parts of the country than others. The Canada Health Infoway, whose mandate is to foster and accelerate development and adoption of electronic health information systems in Canada, suffers from patchwork development and problems with security, privacy and standards.

C.5.1 Identification of First Nations People

As noted in Table 4, there are a number of possible ways to identify First Nations people in health surveillance systems. There is considerable variation and diversity across Canada with respect to the mechanisms that have actually been used. To some extent this variation is determined by what is available and to some extent by history - what work has been initiated, by whom and when. Some examples of where these methods have been used follow:

- Residence on a reserve: Ontario uses a geographic indicator of residence on a reserve (e.g., postal code) to generate information on First Nations residents.

- Identification of health card numbers that belong to First Nations individuals: In Alberta and British Columbia, the health insurance premium database has been linked to health card numbers that identify First Nations status. This has allowed for First Nations utilization and outcome analysis in those provinces.
- Linkage of the Indian and Northern Affairs Canada (INAC) Status Verification System (SVS) database with provincial health databases: There is variation in how method has been used. For example, in Saskatchewan and Alberta the regional First Nation and Inuit Health Branch office matches SVS and provincial birth registry data. In Manitoba the province sends the birth registry to INAC for SVS matching and then forwards the linked file to the First Nation and Inuit Health Branch regional office in Manitoba. British Columbia is the only province that has fundamental First Nations involvement in the process through a Memorandum of Understanding with First Nations leaders for SVS sharing.

In jurisdictions outside of Canada, different methods have been used. For example, the system of U.S. cancer registries operated under the SEER (Surveillance, Epidemiology and End Results) program (these cover about 10% of the U.S. population) includes ethnicity data that are collected at point of contact with the health care system. The SEER registries have closer operational links with at least the hospital portion of the health care system than do most Canadian registries. Furthermore, ethnicity is a mandated variable in the SEER system, in contrast to Canadian registries where, consistent with Canadian values, race and ethnicity data are not captured. In Australia, which, like Canada, has a system of state/territorial cancer registries that together cover the entire country, some cancer registers record Indigenous status but it is of variable completeness and suspect accuracy. Thus, although Indigenous status is captured when available, the end result differs little from that in Canada: surveillance of cancer in Indigenous Australians is not currently possible from cancer registries alone.

C.5.2 Data Linkage Issues

Linkage between databases created for different purposes is complex, particularly in the absence of a high-quality unique identifier that is common to the files to be linked. Thus, although linkage of the SVS and cancer registry is a feasible way of creating a cancer surveillance system for First Nations people, it is not straightforward and is subject to an unknown level of error. This is partly because the personal identification numbers used in the SVS are not unique personal lifetime numbers (a person's number can change for a number of reasons) and differs from the unique identifier in health files (the provincial health insurance number). In the absence of a common unique identifier, links are harder to establish with certainty. The result is that some individuals in the cancer registry who are not First Nations people will be identified as First

Nations and vice versa. Finally, if the SVS is not updated when someone dies or leaves the province, the size of the First Nations population (based on the SVS) will be too large and *rates* of cancer will be underestimated.

C.5.3 Small Numbers

Surveillance data produce the most reliable results when the population under study is large or the health condition very common. Results will then be more accurate and generalizable, and finer groupings, for example by sex, age, cancer type, can be examined. In the case of cancer and First Nations populations:

- The First Nations population is relatively small (even the Ontario First Nations population, which is the largest in Canada, was only 159,000 in 2002);
- Cancer is a rare disease (fewer than 250 cancers are diagnosed in Ontario First Nations people each year in Ontario);
- "Cancer" is actually many different types of cancer which need to be examined separately (because they have different causes, age ranges and outcomes), producing even smaller numbers for each type.

These mean that even in Ontario, rates of less common cancers cannot be estimated reliably and trends over time can be examined only for the most common types of cancer.

C.5.4 Geographic Comparisons

Although it is often most relevant to have data specific to a region or community for local planning, numbers would generally be too small to be meaningful. That said, it is often valuable to examine regional variation at the geographic level permitted by the data. Examination of cancer patterns in Native Americans in different parts of the U.S. showed striking differences (see Table 2). Such comparisons can generate hypotheses to test. For example, geographic differences in cancer mortality noted in the U.S. could be examined in relation to variations in risk factor prevalences if these were available. In Saskatchewan, comparisons of cancer survival for northern First Nations, northern non-First Nations, southern First Nations and southern non-First Nations were made, to indirectly examine the impact of remoteness as well as First Nations status.

C.6 The Case for a National First Nations Cancer Surveillance System

The case for systematic cancer surveillance rests on the premise that high-quality, routinely-collected, timely data are required for planning to reduce the burden of cancer. Setting priorities for cancer prevention, screening, diagnosis, care and research; monitoring progress; evaluating programs and other interventions; advocating for resources; and projecting future cancer burden require information about the numbers of cancers, trends over time and survival following the diagnosis of cancer. These data are difficult and expensive to collect, yet they already exist in provincial/territorial cancer registries and are being used for these very purposes in the population as a whole. What does *not* currently exist is the ability to produce these types of data

separately for ethnically-defined subgroups of the population who may have very different cancer patterns and needs. It is feasible to produce these data for First Nations people, as has been done periodically in a number of Canadian jurisdictions.

The case for a *national* system rests on the following:

- A strong system of cancer registries exists in Canada already.
- Every province/territory has a high-quality cancer registry covering its population.
- The provincial/territorial cancer registries combine data to produce a Canadian Cancer Registry that covers the entire country. There are relatively few countries in the world that have such national coverage.
- Each province/territory has a relatively small population of First Nations people, resulting in unstable estimates of cancer incidence and mortality at the provincial level. This limits utility of the data. A national system would be much more valuable, providing, for example, opportunity to track cancer trends over time for a wider variety of cancer types.
- Some First Nations may have more in common with neighbouring First Nations communities in the adjacent province than they do with distant First Nations within their own provinces. A national system would permit more rational aggregation of communities across provincial boundaries. (The same applies to Native American populations in adjacent states, which speaks to the potential value of international collaborations.)
- There is potentially much to be learned from geographic comparisons. This would be much greater nationally than provincially.
- The obstacles to creating First Nations cancer surveillance systems are considerable. Sharing the burden of developing workable solutions across provinces is efficient. This does not mean that the same model should be established everywhere – the system will be stronger if alternative models are developed.
- Some provinces/territories do not currently have the capacity or the will to develop provincial First Nations cancer surveillance systems. Development of systems in provinces that are ready to do so may assist other provinces in doing the same in the longer term.

C.7 Developing a National First Nations Cancer Surveillance System

C.7.1 Initiatives Underway

A number of promising initiatives relevant to development of First Nations cancer surveillance were identified. These can provide some foundation or serve as models:

- The First Nations Longitudinal Regional Health Survey (RHS) demonstrates OCAP principles in action. Important features include:
    - Code of Research Ethics
    - Partnerships with all First Nations regional leadership organizations
    - Autonomous and First Nations-owned infrastructure
    - Holistic health framework
    - Data Sharing Framework Agreement between the First Nations Information Governance Committee and Health Canada

- The Assembly of Manitoba Chiefs has developed a collaborative relationship with the University of Manitoba in capacity-development and research.
- Eskasoni First Nation has worked in partnership with Health Canada and the Nova Scotia government.
- The Institute of Aboriginal Peoples' Health has research funding and capacity-support programs such as the Aboriginal Capacity and Developmental Research Environments (ACADRE), and has influence over policy-relevant research agendas, e.g., suicide prevention.
- In British Columbia, there is a tri-partite agreement for the sharing of First Nations health information.

C.7.2 Critical Issues

Workshop participants discussed issues that are critical to the development of a national First Nations cancer surveillance system:

- The need for and benefits of having such a surveillance system or systems – nationally, provincially/regionally, and at the community level;
- Fulfillment of the principles of OCAP;
- Identification of the key partners in moving the discussion forward and taking action; and
- Adequate funding for developing both protocols and sustainable data systems.

First Nations representatives supported the need for more and better health data about First Nations peoples. Ownership, Control, Access and Possession are the principles upon which First Nations representatives will proceed with the development of First Nation cancer surveillance systems. This has implications at the community level, regionally, and nationally for the development of First Nations capacity, and for relationships with cancer agencies, researchers and government officials.

The First Nations Centre of the National Aboriginal Health Organization identified the need for partnerships to:

- Work with those that share First Nations values;
- Access technical and financial resources;
- Influence policy; and
- Build sustained infrastructures for integrated, comprehensive, First Nations-driven research and surveillance.

C.7.3 Moving Forward

Participants demonstrated an interest in developing a national group or forum to explore development of a national First Nations cancer surveillance strategy, although the implementation of a national system is seen as a long-term undertaking. As a first step, NAHO volunteered to bring together interested workshop participants with the First Nations Governance Committee.

There was agreement that the more immediate work will take place at the provincial and community level. Provincial cancer agencies are critical partners in working with regional First

Nations representatives on protocols for data sharing, on understanding the data, and on developing responsive programming. British Columbia, Manitoba, and Ontario are all making progress and could work together to move things forward, in cooperation with appropriate national agencies. The first step could be the development of a plan with the following characteristics:

- A provincial focus but with due consideration to the production of regional information;
- Governance, ownership and use of data systems consistent with OCAP principles and with good ethical practices to ensure protection of privacy and confidentiality;
- An identified physical "home" for the surveillance system;
- Integration of the requirements of the various jurisdictions with relevant responsibilities and interests (e.g., national, provincial/regional governments; First Nations organizations; cancer agencies);
- Incorporation of a plan for building capacity in First Nations communities; and
- An appropriate consultation process with Aboriginal organizations and communities, including ongoing communication.

D Summary and Next Steps

D.1 Summary

The primary objectives of the First Nations Cancer Research and Surveillance Workshop were met. Research gaps and priorities were identified, and the workshop participants discussed and identified the critical political, ethical, technical and scientific issues in conducting research in First Nations populations.

Progress was made on the objective to establish networks for collaboration. Tentative plans were made for working with the Indian Health Service in the mainland U.S. and Alaska to produce cancer statistics for American and Canadian aboriginal populations and to compare cancer burden across North America using similar methodology. This could provide important clues about etiology.

It was intended that the workshop would also provide a forum for discussion of the need for a national First Nations cancer surveillance system. First Nations people had the opportunity to discuss with each other and with government representatives and researchers the potential value of such a system and the principles upon which it would have to be established and managed.

D.2 Next steps

This workshop is an important first step in what must be an evolutionary process. Additional steps include:

1. Disseminate the workshop findings:
   - Forward the identified research priorities to the workshop funders (National Cancer Institute of Canada, Canadian Institutes of Health Research (Institute of Cancer Research and Institute of Aboriginal Peoples' Health), Canadian Population Health Initiative).
   - Circulate this report widely, to workshop participants, cancer agencies, government departments and Aboriginal organizations.
   - Post the report and workshop materials on the Cancer Care Ontario website.
   - Publish an abbreviated version of the report in Canadian journals such as Chronic Diseases in Canada and the Journal of Aboriginal Health.

2. Determine how cancer surveillance could be implemented consistent with OCAP:
   - The National Aboriginal Health Organization will facilitate a meeting with the First Nations Governance Committee.

3. Develop provincial-level strategies:
   - Provinces with capacity and interest will consult with their stakeholders, including Aboriginal and First Nations groups, cancer registries, provincial governments, etc. as appropriate to identify feasible strategies.

In the province of Ontario, for example, the Aboriginal Cancer Care Unit (ACCU) at Cancer Care Ontario is well-positioned to take the lead, with support from the Joint Cancer Care Ontario Aboriginal Cancer Committee (JOACC). Specifically, the Aboriginal Cancer Care Unit will work with the Surveillance Unit on a recommendation to present to the JOACC, requesting support for the ACCU Director to meet with the Chiefs of Ontario Health Committee to discuss possible options for developing a First Nations cancer surveillance system in Ontario. Scientific and technical staff in the Surveillance Unit are already collaborating with ACCU to generate relevant statistics about the burden of cancer in Ontario First Nations people, based on the province-wide population-based cancer registry. This collaboration can continue within the new model developed to be consistent with both OCAP and the ethical guidelines established by the Ontario Cancer Registry.

Appendices

A: First Nations Cancer Research and Surveillance Workshop: Agenda

B: Participant List

C: Bibliography of Recent Cancer-Related Publications in North American Aboriginal Populations

D: Benefits of a Cancer Surveillance System for Canada's First Nation Peoples: Issues Paper

Appendix A

First Nations Cancer Research and Surveillance Workshop
September 23-24, 2003
AGENDA

September 23:

8:00	**Continental Breakfast available**
9:00	**Opening Prayer,** Elder Roger Jones
9:30	**Introductions**
10:00	**Opening Remarks**
10:45	**Break**

Research Findings

11:00	**Presentations from Cancer Care Ontario:**
	Cancer Incidence and Mortality in Ontario First Nations - Loraine Marrett
	Findings of the Aboriginal Cancer Care Needs Assessment – Carmen R. Jones
12:00	**Lunch**
1:00	**Panel Presentations:**
	Cancer research in First Nations communities - Alain Demers, Cancer Care Manitoba
	Cancer in the First Nations of British Columbia - Andy Coldman, British Columbia Cancer Agency
	PAP screening among First Nations women in Vancouver - Greg Hislop, British Columbia Cancer Agency
	A review of cancer in Indigenous Australians - John Condon, Menzies School of Health Research
	Cancer surveillance system for Aboriginal Alaskans: 30+ years of data - Christine DeCourtney, Alaska Native Medical Center

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2:30 **Break**

Research Priorities

2:45 **Small group discussions** about research priorities, followed by plenary.

4:00 **Presentation**: Diabetes and cancer - Gail Eyssen, University of Toronto

4:30 **Adjourn**

6:00 **Reception**

7:00 **Dinner with Keynote Speaker, Charles Fox, Vice Chief of the Assembly of First Nations, and Regional Chief of Ontario**

September 24:

8:00 **Continental Breakfast available**

Surveillance

9:00 **First Nations Perspectives on health research and surveillance** – Presentation by Allen DeLeary, National Aboriginal Health Organization

9:45 **Surveillance in First Nations communities – issues and considerations**
Presentation by John O'Neil, University of Manitoba

10:30 **Break**

10:45 **Panel Presentations**

Developing a cancer surveillance system - David Espey, US Indian Health Service

Cancer surveillance for Indigenous Australians - John Condon, Menzies School of Health Research

Challenges of data collection – Rene Dion, Health Canada

A method for estimating cancer rates in First Nation communities - Grace Johnston, Dalhousie University

Issues in developing a cancer surveillance system for Ontario – Loraine Marrett, Cancer Care Ontario

12:00	**Lunch**
1:00	**Options for moving forward** – Terry Sullivan, Cancer Care Ontario
1:30	**Small group discussions** about surveillance options and opportunities
2:30	**Break**
2:45	**Plenary session** – reports from small group discussions
3:30	**Next Steps and Wrap Up** – Terry Sullivan, Cancer Care Ontario
4:00	**Closing Prayer**, Elder Roger Jones

Appendix B: Participant List

First Nations Cancer Research and Surveillance Workshop
September 23-24, 2003
Ottawa

Invited Guest:	Affiliation:
Andre Allard	Health Canada
Riaz Alvi	Saskatchewan Cancer Care
Tracy Antone	Chiefs of Ontario
Carol Burke	Ontario Federation of Indian Friendship Centres
Shirley Bryan	Health Canada
Judy Chapman Price	Ontario Métis Aboriginal Association
Andrew Coldman	British Columbia Cancer Agency
Laura Commanda	Canadian Institutes of Health Research
John Condon	Menzies School of Health Research (Northern Territory, Australia)
Christine DeCourtney	Alaska Native Tribal Health Consortium (U.S)
Allen Deleary	National Aboriginal Health Organization
Alain Demers	Cancer Care Manitoba
Ron Dewar	Cancer Care Nova Scotia
Thomas Dignan Health	Canada
Rene Dion	Health Canada
David Espey	Indian Health Service (U.S.)
Martha Fair	Statistics Canada
Vice-Chief Charles Fox	Assembly of First Nations
Ann Hamilton	Ontario Native Women's Association
Anthony Hanley	Mount Sinai Hospital
Barb Harris	Six Nations Health Council
Sylvia Healy	Nunavut Department of Health
Valerie Hepburn	Canadian Cancer Society
Greg Hislop	British Columbia Cancer Agency
Grace Johnson	Dalhousie University
Elaine Johnston	Assembly of First Nations
Carmen Jones	Cancer Care Ontario
Elder Roger Jones	Shawanaga First Nation
Deanna Jones-Keeshig	Shawanaga First Nation
Kevin Keough	Health Canada
Erich Kliewer	Cancer Care Manitoba
Marie-France Lamarche	Health Canada
Bryan LeFrance	Statistics Canada
Mary Lynch-Taylor	Union of Ontario Indians
Betsy Mandamin	Grand Council Treaty #3
Cathryn Mandoka	Association of Iroquois and Allied Indians
Dawn T. Maracle	Cancer Care Ontario
Loraine Marrett	Cancer Care Ontario
Yang Mao	Health Canada
Chief Lucy McGinty	Selkirk First Nation
Gail McKeown-Eyssen	University of Toronto
John McLaughlin	Mount Sinai Hospital
Alison McMullen	Cancer Care Ontario
Terry Mitchell	Wilfred Laurier University

Invited Guest:	Affiliation:
Roger Neufeld	Health Canada
Diane Nishri	Cancer Care Ontario
John O'Neil	University of Manitoba
Chief Emma Palmantier	Lake Babine Nation
Louise Pelletier	Health Canada
Ian Potter	Health Canada
Adam Probert	Health Canada
Monique Raymond	Métis Nation of Ontario
Maria Santos	Northwest Territories, Department of Health and Social Services
Farrah Schwartz	Cancer Care Ontario
Chandrakant Shah	University of Toronto
Terrance Sullivan	Cancer Care Ontario
Bronwyn Shoush	Alberta Solicitor General
Soo Hong Uh	British Columbia Vital Statistics Agency
Kue Young	University of Toronto

Appendix C:

Bibliography of Recent Cancer-Related Publications in North American Aboriginal Populations

Prepared For:

First Nations Cancer Research and Surveillance Workshop
September 23-24, 2003
Ottawa

2004

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Appendix D:

Benefits of a Cancer Surveillance System for Canada's First Nation Peoples: Issues Paper

The Royal Commission on Aboriginal Peoples (RCAP) stressed that "Aboriginal governments would need at their disposal, the human resource skills, technologies and equipment necessary to meet the challenges of managing information in an Aboriginal government with confidence". The RCAP further stated that *"information management systems in support of self-government should allow for controlled access to confidential information, collection and analysis of information within and across communities in a nation, pooling of information among multiple Aboriginal nations, and maximum compatibility with Canada-wide statistics gathered by Statistics Canada."*

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Key Issue

An adequate cancer surveillance system could support the development of initiatives and strategies to reduce the burden of cancer in First Nation populations.

Relevant Facts

Definition of Surveillance. *Surveillance is "the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice" (O'Neil JD, 2001). A surveillance system, as opposed to periodic surveillance, takes place on an ongoing and regular basis. An ongoing surveillance system is better than ad hoc surveys for a comprehensive picture of population health needs. A surveillance system can have several uses for a public health issue:*

- Providing quantitative estimates of the magnitude of a health problem (measures of mortality, morbidity, incidence, for example)
- Describing health outcomes for a disease
- Detection of 'epidemics' and areas of priority need (can be communicable and non-communicable diseases)
- Documentation of the distribution of health events/states
- Evaluation of prevention/control measures
- Monitoring changes in the frequency and distribution of a health event over time.

Examples of current public health surveillance systems in Canada include the Ontario Cancer Registry, the Canadian Injury Surveillance Program, run by the Population and Public Health Branch of Health Canada, and the West Nile Virus Surveillance Program run by the Ontario Ministry of Health.

All provinces maintain cancer surveillance systems— ongoing, population-based, computerised databases of information on all provincial residents who have been newly diagnosed with cancer or who have died of cancer. They are generally referred to as 'registries'.

Burden of Cancer within Canada's First Nation Populations. Cancer is a significant cause of illness and death in First Nation populations, ranking third as a cause of death after heart disease and accidents, suicides and homicides (Marrett LD and Chaudhry M, 2003). In the general population, incidence and mortality rates of cancer have been stable or declining for all cancers combined over the past decade. However, based on past cancer trends and information on risk factor prevalence in First Nation communities, cancer rates are likely to increase among First Nation populations over the coming decade. Many cancers are preventable or treatable in their early stages; it is therefore imperative to develop appropriate primary prevention (eliminating cancer risk factors) and secondary prevention (early detection of cancer or its precursor so that it can be treated easily and effectively) strategies.

Challenges for First Nation Cancer Control. A number of challenges are unique to First Nation populations and must be considered in analysing cancer-related issues. These include:

- Life circumstances over which First Nation peoples have no control have put them at higher risk for poor health. These circumstances include reserve systems that dictate where they can live, low housing standards, poor water quality and a lack of resources to correct various inequities, to mention a few. First Nation populations must also cope with a highly complex and fragmented health care system that is under provincial, federal and First Nation jurisdictions. This system operates very differently and perhaps less efficiently than those systems that general residents of Canada utilise.
- A myth that cancer is rare among First Nation people. This belief, widespread in Aboriginal health literature, can contribute to late diagnosis and misdiagnosis of cancer by health professionals, much like the fact that heart disease in women has traditionally been a neglected health area.
- Culturally appropriate information about cancer is not readily available to First Nation populations. This is partially due to the remoteness for the large northern population, limited access to First Nation health professionals who would be aware of cultural nuances and an overall lack of culturally sensitive materials and consistent funding to support these things.
- The age distribution of First Nation populations differs from the rest of Canada's population. Whereas Canada's non-First Nation populations are predominantly older, First Nation populations are young and growing. The number of new cancer cases can be expected to increase as First Nation populations age.
- The concept of disease management is very different in First Nation populations. The western concept of disease treatment and cancer-site-management is not readily accepted in many First Nation cultures, which place high importance on the holistic model of health.
- There is a lack of research and cancer surveillance data that are specific to First Nation populations.

Inability to Define Needs among First Nation peoples. *There are relatively few studies of cancer mortality and incidence among First Nation peoples in Canada. The Canadian studies published to date have had limitations that have restricted the generalizibility and validity of their findings. These studies often have small samples. Many are published in medical journals from the United States where culturally sensitive research and conferences on cancer in Native Americans are more prevalent and where issues of law, regulation and identification sometime differ. In Canada, information about cancer control needs comes primarily from research conducted in the North West Territories, British Columbia, Saskatchewan, and more recently, Ontario.*

Practical Considerations:

There are several methods for identifying First Nation individuals in provincial health databases[2]:

[2] The noted methods used by each province are subject to verification.

- Identification of health card numbers that belong to First Nation individuals. In Alberta and British Columbia, the health insurance premium database has been linked to health card numbers, which has allowed for First Nation utilisation and outcome analysis in those provinces.
- Utilisation of a geographic indicator such as postal codes or residency codes that belong to First Nation individuals on reserve. With this method, all records of residents in selected areas will be extracted, not just First Nation individuals, and First Nation people living off reserve will not be included. Currently, Ontario uses a geographic identifier to provide information on First Nation residents.
- Linkage of the Department of Indian Affairs and Northern Development (DIAND) Status Verification System (SVS) database with provincial health databases. The SVS contains the information of all registered First Nation individuals, living on or off reserve, who are eligible for federal benefits through DIAND or First Nations and Inuit Health Branch (FNIHB). FNIHB has recently established a policy that sharing of SVS data with the province would require First Nations approval and participation.

There are also ethical issues involved with data collection and management. Data collection by external agencies can be perceived as oppressive and as having the effect of perpetuating colonial relationships between two populations. Results can also paint an unfavourable picture of First Nation populations that can be misinterpreted by the Canadian media and poorly reported to the general population. For these and other reasons, data collection and management can be difficult issues to maneuver.

On the other hand, the collection of data plays a key role in the development of a First Nation health infostructure. Ownership, control, access and possession (OCAP) of health information are key components of self-government. OCAP can directly address many of the ethical concerns of data collection and management by external agencies, while contributing to First Nation capacity-building at the same time. For this reason, data collection and management, provided that information OCAP remains with First Nation authorities, will propel self-government forward.

First Nation Population Across the Country. The distribution of First Nation populations across Canada is uneven (see Table 1) and the size of the populations may be considered in the development of a cancer surveillance pilot.

Table 1: Provincial breakdown of First Nation populations across Canada

Region	Number of bands	Members A+B+C	On Reserve (A)	On Crown Land (B)	Off Reserve (C)
Atlantic	33	28,819	17,670	20	11,129
Quebec	39	65,496	44,415	1,299	19,782
Ontario	126	159,107	78,936	1,280	78,891
Manitoba	62	112,430	70,426	1,655	40,349
Saskatchewan	70	111,635	54,733	1,831	55,071
Alberta	44	89,812	56,328	2,718	30,766
British Columbia	198	114,120	56,828	423	56,869
Yukon	16	7,846	487	3,424	3,935
Northwest Territories	26	15,586	244	10,620	4,722
Canada	614	704,851	380,067	23,270	301,514

Source: Department of Indian Affairs and Northern Development Registered Indian Population by Sex and Residence, 2002

Recommendations from Previous Studies

In 2001, John D. O'Neil and James Blanchard[3] explored the possibility of developing public health surveillance systems in First Nation communities. Their report included the following relevant recommendations about public health surveillance:

1) The development of a First Nation Health infostructure and the development of public health surveillance systems must be given higher priority by First Nation, federal and provincial leaders.

2) The focus for development should be on the establishment of multiple surveillance systems focusing on specific public health problems rather than a single omnibus national health infostructure or "public health surveillance system" for First Nation communities.

3) First Nation communities and/or organisations need to continue to develop their own capacity to perform the analytical and dissemination functions of a public health surveillance system supported by both federal and provincial governments.

4) Consideration should be given to creating a series of regional analytic resource centres that could provide broad technical support to communities and organizations within their regions.

5) In the short term at least, First Nation regional analytic centres for health information and public health surveillance will likely involve collaborations and partnerships among First Nation authorities, federal and provincial agencies and relevant University centres.

[3] John D. O'Neil & James Blanchard. (October, 2001). "Consideration for the Development of Public Health Surveillance in First Nations Communities". Department of Community Health Sciences, University of Manitoba. Pp. 6- 7.

6) A national First Nation Health Surveillance Committee (FNHSC) should be established to oversee and support health surveillance activities at the regional level, and to ensure that standardisation of health information systems across regions is achieved.

7) The national FNHSC should also take on responsibility for ensuring that OCAP principles are fundamental to further health infostructure development, and that issues of individual confidentiality and consent to have health data used for research purpose are taken into consideration.

8) Targeted "pilot" health surveillance projects should be established under the direction of both regional and national planning committees that will provide the opportunity for the various partners to develop the capacity to work together in an environment of mutual trust and respect.

Cancer and Surveillance System. *Cancer presents advantages for the development of a disease-specific surveillance system when considering where to begin developing public health surveillance systems in general. A cancer surveillance system based on provincial/territorial cancer registries is already in place across the country. Cancer registries in most jurisdictions are housed in cancer agencies separate from provincial governments. The key step to creating a First Nation cancer surveillance system would therefore be to identify relevant sub-populations, as opposed to having to identify those with specific diseases as would have to be done if a surveillance system were not already in place. The ability to begin to develop the surveillance system from a set point, rather than from scratch, is an important advantage in the consideration of developing a cancer-specific surveillance system for First Nation populations.*

Moving Forward

One option for moving forward, as recommended by O'Neil (2001), is to develop a provincial pilot cancer surveillance system. A pilot study can have several benefits:

- *It is a step forward that can take place in the absence of a national strategy*
- *It provides practical experience for other provinces to develop systems*
- *It can build momentum for the development of a national strategy*
- *A pilot can help fine-tune data extraction methodology prior to full-scale implementation*

If a pilot is determined to be the next step in moving forward, several criteria could be considered for the development of the pilot and the selection of the site in which the pilot could take place.